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ABSTRACT

The review of the literature examines issues concerned with the use of psychotropic medication by people with severe disabilities living in community settings. Data on prevalence of drug usage are provided and include that 54.3% of residents of community residences receive some type of prescribed medication, most of which are classified as psychotropic or psychoactive. A number of studies are reviewed which question the appropriateness of such massive use of medication. Additional studies have concerned behavioral toxicity, the tendency of psychotropic drugs to suppress desirable as well as problem behavior, and side effects such as tardive dyskinesia. Support for responsible use of medication stresses the role of direct service workers and the use of community physicians. It is concluded that: (1) most people with severe disabilities do not need to be on behavior altering drugs; (2) this standard practice does not aid integration; (3) widespread use of psychotropics is probably indicative of a program which is focused on controlling groups rather than aiding the integration of individuals into the community; (4) the use of medication must be individualized; and (5) management of psychotropic medication is a generic service which people with severe disabilities can receive in the community. (DB)

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PSYCHOTROPIC MEDICATION AND COMMUNITY INTEGRATION: IMPLICATIONS FOR SERVICE PROVIDERS

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> Needless to say, psychotropic drugs have enabled many mentally retarded individuals to lead more independent lives and have facilitated integration into the community (Agran & Martin, 1982, p. 57).

> Some subjects had been included in the group [receiving medication] for reasons such as "masturbates too much" or "talks back to staff" (Bates, Smeltzer, & Arnoczky, 1986, p. 368).

> There is an economic incentive for the caregiver to bring client behavior under control by non-labor intensive means,...it is not uncommon to hear tales of the physician who stops in the board and care home once a month, spends sufficient time there to sign for medications, bills Medicaid, and returns again the following month for the same purpose (Mouchka, 1985, p. 266).

> The supervisor of his community apartment...felt that medications of all sort were improperly used and badly reviewed. Accordingly, she told Hugh's psychiatrist that Hugh should be stopped immediately from any further medication. His psychiatrist agreed and within a few days Hugh was shouting, throwing dishes, and generally frightening others. He was immediately put back on medication, and the persons working with him decided that he really did need to be maintained on Mellaril (Lovett, 1985, p. 124).

Many advocates of community integration emphatically oppose the the use of psychotropic medication by people with developmental disabilities. Is this a rational position or is it merely an over reaction to the use of these medications as "chemical straitjackets?" Can psychoactive drugs really aid people's integration into the community? Or are those who dispense drugs merely "agents of control for the powerless by the powerful, means of preserving the status quo" (Mouchka, 1985, p. 266)?

The intent of this report is to examine these issues

and others related to use of psychotropic medication by people with severe disabilities in the community. The aim of this review is to distill the information in some of the recent research in medicine and developmental disabilities in an attempt to give service providers, advocates, and family members a sense of what seems to be the state of knowledge on use of behavior altering drugs. The focus is not to critique the quality of the research--professional journals provide more than enough space for that--but to focus on the practical implications of this information.

While the focus of this report is on people with severe disabilities living in the community, a quick glance at the reference list will reveal a number of citations dealing with people in institutions. This is because most of the basic research in this area is being done with the population of institutions. This raises a couple of interesting questions which are hinted at or mentioned in the literature. 1) Should we be concerned about academic psychiatry's attachment to institutional settings where it is so much easier to carry out "clean" well controlled experiments (cf. Mouchka, 1985)? 2) How valid is research which goes beyond describing clinical facts (e.g., blood levels of certain medication) and uses behavioral observation yet does not take into account the debilitating and stultifying effects of living in an institutional environment? These are raised here simply to alert the reader to a proviso which must be kept in mind when

reviewing any institution-based research with an eye to its implications for people living in the community.

Prevalence

A survey of drug usage in a national sample of state institutions and community residences for people with mental retardation reveals that 75.8% of the people residing in state institutions and 54.3% of community residents are receiving some type of prescribed medication (Hill, Balow, & Bruininks, 1985). Most of these people are taking drugs which are classified as psychotropic or psychoactive. Specifically, in the community sample 21.5% take an anticonvulsant, 25.9% are on some other psychotropic, and 20.5% take a major tranquillizer (Table 1 provides an overview of these classes of drugs, their names, and intended effect). In the institutional group 36.3 % take anticonvulsants, while 37.9% have prescriptions for psychotropic and 29.9% are receiving major tranquillizes. On closer examination these figure, while instructive are difficult to interpret since it is not at all clear how people receiving more than one drug were classified and the figures as reported do not total properly.

A parallel study of drug usage in community and institutional settings in the state of Missouri, provides a somewhat clearer analysis of its data (Intagliata & Rinck, 1985). Here the overall rate of prescribed medication was 89% in institutions and 63.6% in the community. Table 2

Table 1
Selected List of Psychotropic Drugs by Classification, Generic Name, Trade Name, and Common Therapeutic Use

Classification	Generic Name	Trade Name	Therapeutic Use
Anticonvulsant	Mysoline Phenobarbital Phenytoin	Primidone Dilantin	Treatment and management of convulsions; antiepileptic
Antidepressant	Amitriptyline Imipramine Phenelzine	Elavil Tofranil Nardil	Suppression of depression; mood elevator
Stimulant	Cylert Dextroamphetamine Methylphenidate	Pemoline Dexedrine Ritalin	Management of hyperactivity; also controls drowsiness
Minor tranquilizer	Clonazepam Chlordiazepoxide Diazepam	Clonopin Librium Valium	Control of anxiety
Major tranquilizer	Chlorpromazine Haloperidol Thioridazine	Thorazine Haldol Mellaril	Treatment and management of psychotic disorders
Sedative-hypnotic	Mephobarbital Pentobarbital Secobarbital	Mebaral Nembutal Seconal	Management of anxiety; also used to induce sleep
Anticholinergic	Benztropine Cycrimine Trihexphenidyl	Cogentin Pagitane Artane	Management of extrapyramidal symptoms (i.e., side effects) associated with antipsychotics

Adapted from Agran and Martin, 1982, p. 57

summarizes the prevalence of psychoactive drug usage in general and in combination as found by this study. The pattern reported here is very similar to what was found by Hill et al. but some of the percentages are substantially higher. For example, major tranquillizers are exceeded only by anticonvulsants as the most frequently prescribed class of medication but in this study 28.8% of the community sample and 45% of the institutional sample took these drugs.

Both of these studies found a relationship between living environment and the probability of drug use. Intagliata and Rinck found that residents in institutions were significantly more likely to be on medication. Hill and his colleagues found a that the usage of drugs increased as the staff to resident ratio grew (i.e., as there were more residents per staff member).

In a study which examined drug use across a full range of community vocational and residential programs, Martin and Agran (1985) found that 48% of adults with mental retardation took some form of psychotropic and/or anticonvulsant medication. Further, they found that 70% of the people in their sample with an institutional history took a prescribed drug while only 27% of those who had always lived in the community were on medication. When the nature of the environment was examined they discovered that as the residential or vocational setting became more

TABLE 2

PREVALENCE OF PSYCHOTROPIC USAGE IN GENERAL AND OF SELECTED DRUG TYPE COMBINATIONS

MEDICATION	COMMUNITY RESIDENTS (N=295)	INSTITUTIONAL RESIDENTS (N=171)
Psychoactive Drugs	47.5%	76 %
Psychotropics only	26.8	34.5
Anticonvulsant only	11.2	21.6
Psychotropics & Anticonvulsant	9.5	19.9
Total Psychotropics (alone or in combination)	36.3	54.4
Total Anticonvulsant (alone or in combination)	20.7	41.5

Adapted from Intagliata & Rinck, 1985, p. 272

restrictive the use of anticonvulsant and psychotropic drugs increased dramatically.

Appropriateness

This massive use of medication in itself is a subject for concern, but the problem is underscored when the analysis becomes a bit more focused and examines issues such as the appropriateness of the particular medication which people receive and dosage levels.

In an article written to assist community medical providers in serving individuals who are leaving mental retardation institutions, Merker and Wernsing (1984) suggest that most of the psychotropic medication prescribed for these people is inappropriate. "These medications were used to 'control' behavioral problems in institutionalized patients, instead of attempting to modify the underlying problem" (p. 230). This contention is supported by examining statistical data on the incidence of psychiatric illness in people with mental retardation. They point out that the treatment of choice for most of these disorders is environmental and behavioral modification.

The position of those who contend that drugs are widely misused was further strengthened by a 1986 study by Bates, Smeltzer, and Arnoczky which examined the appropriateness of the drug regime of 242 institutionalized people with mental retardation. As a standard they used what they identified as the "conservative" (i.e., tending to favor the use of

medication) guidelines of the American Psychiatric Association peer review manual. Under these conditions 39.1% to 54.6% of the drug treatment regimes were found to be inappropriate for the conditions diagnosed. They were particularly concerned about the administration of drugs to people whose only diagnosis was mental retardation--all of these are defined as an inappropriate use of medication.

The problem of appropriate medication is somewhat different when we shift our focus from tranquillizers to anticonvulsants. It appears that a substantial number of people receiving anticonvulsants are receiving unnecessary drugs or are being over medicated. For example, approximately 28% people with mental retardation receiving phenytoin have not had an observable seizure (Davis, Cullari, & Breuning, 1982). In an examination of the the drug level of a sample 175 individuals taking anticonvulsants, Aman, Paxton, Field, & Foote (1986) found that as many as 16% of the people taking carbamazepine and 28% of those taking phenytoin had levels in the toxic range. They conclude: "Although not all of the subjects with concentrations exceeding the therapeutic range would have experienced toxic effects, it is also likely that some within the therapeutic range, but at the upper end would have experienced intoxication. Thus, the figures...are justification for concern, and they suggest that large numbers of retarded people (especially those on phenytoin) may be receiving excessively large doses of anticonvulsant

medications" (p. 648). What these studies on the use of anticonvulsants highlight is the need for thoughtful system of drug management. In most of the cases reported here the medication itself was appropriate for treatment of a specific disorder, but the monitoring of these drugs was woefully inadequate.

These findings on the drugs are enough in and of themselves to merit a serious questioning of most medication usage. However, as yet we have not touched a major rationale for minimizing the use of drugs in the community--the ability of most psychotropic medications to interfere with learning and adaptive behavior.

Behavioral Toxicity

In a 1982 article, which was the first published attempt to examine the limited literature on the use of psychotropic medication in community programs for people with mental retardation, Agran and Martin call particular attention to the issue of behavioral toxicity. This term refers to the tendency of psychotropic drugs to suppress all behavior, desirable, functional, adaptive behaviors as well as the target "problem" behavior.

The deleterious effect of psychotropic medication on adaptive behavior has frequently been reported in the literature. Aman (1983) reported that higher doses of psychotropic and anticonvulsant medication hinder the learning of people with mental retardation. In 1981 Wysocki

and his colleagues (Wysocki, Fuqua, Davis, & Breuning) demonstrated a connection between administration of thioridazine and impaired performance on task requiring discrimination. In addition, phenytoin (Davis, 1982) have been shown to impair the performance of workshop tasks. In summarizing a series of four experiments Ferguson (1982) concludes that a variety of psychoactive drugs: "1)..do not reduce inappropriate behavior; 2) interfere with responding to reinforcement contingencies; and 3) interfere with the performance of workshop tasks" (p. 56). The single study which seems to contradict these findings confines itself to observing increase in inappropriate behavior, subsequent to a drug holiday, on a living unit of an institution (Heistad, Zimmermann, & Doebler, 1982). In their conclusion, the authors of this study allow that their findings may be contaminated by the subject's initial withdrawal reaction since the drug free period was relatively short. Also, they point out that a number of the residents in the study were identified as candidate to be withdrawn from medication.

While it is not unequivocally reported that behavioral toxicity is related to dosage level, good clinical procedure dictates that the minimum effective dose of a medication is preferable. Two studies of the effects of dosage level of thioridazine confirm that in general people with mental retardation are receiving a higher level of this medication than is needed to obtain the desired effects. Singh and Aman (1981) found that a dose less than half of what was standard

practice was equally effective for a group of 20 individuals labeled as severely retarded and living in an institutional setting.

Side Effects

A final major problem associated with the long term use of high doses of psychotropic medication is the possibility of a permanent severe and even life threatening syndrome called tardive dyskinesia (and other associated extrapyrimidal symptoms). It is marked by abnormal involuntary movements such as grimacing, blinking, lip smacking, tongue thrusting and unusual twisting of hands and fingers (Sprague et al., 1984). Development of this disorder appears to be associated with cumulative dose of psychotropic drugs (Gualtieri, Quade, Hicks, Mayo, & Schroeder, 1984). Most instance of dyskinesia are not evident while the person continues to take medication. Once medication is withdrawn this syndrome becomes evident. However, many of the dyskinetic movements which arise during the first 4 weeks after medication is withdrawn are a withdrawal reaction and not true tardive dykinesia. They will spontaneously remit (Gualtieri, Breuning, Schroeder, & Quade, 1982). In addition this withdrawal dyskinesias is often accompanied by a behavioral problems which are often different from the behavior which preceded the use of medication. And, like the withdrawal dyskinesia, this withdrawal behavior will usually subside spontaneously.

Therefore, physicians are advised not to resume the use of medication in the face of this initial burst of problem behavior since the vast majority of those exhibiting it will in fact be able to remain drug-free. This is a particularly crucial consideration given the potential for long term tardive dyskinesia if the person returns to and remains on the medication for a prolonged period (Gualtieri et al. 1982, 1984).

Responsible Use of Medication

Despite the obvious problems resulting from the overuse of psychotropic medication on people with mental retardation, many experts in the field claim that for a small percentage of these people with serious mental health problems, such as schizophrenia, an individualized closely monitored drug regime can be effective (Menolascino, Wilson, Golden, & Ruedrich, 1986; Merker & Wernsing, 1984). In these cases medication is viewed as only one element in a total plan of services which takes into account the demands and supports presence in the community within which the person must function. The drugs are seen as an adjunct to services not a substitute (Schalock, Foley, Toulouse, & Stark, 1985).

Role of Direct Service Workers

The role of community service providers in monitoring medication has not been systematically explored in the literature. But, there is some suggestion in the

institution-based literature on the appropriate role of staff people in managing drugs.

Most states mandate a similar training module on medication for both institutional and community employees (e. g., Living Resources Corporation, 1984; McCarthy, 1980). However, the mountain of detailed information concerning types of medication, possible side effects, and clinical procedures for dispensing medication is geared toward managing the drug supply of a facility rather than working with individuals to monitor their own use of medication (cf. Knoll & Ford, in press). This type of training has not been shown to serve the best interest of people with mental retardation. In fact, settings where staff have received this standard training and medication decisions are based, as the frequently are, on reports from direct service personnel have witnessed the inappropriate and over use of medication (Bates, Smeltzer, & Arnoczky, 1986). On the other hand, in circumstances where staff people have been sensitized to issue surrounding medication and focused on the specific needs of individuals there has been a positive impact (i.e., a decrease) on the use of psychotropic drugs (Davidson, Hemingway, Wysocki, 1984; Ferguson, Cullari, Davidson, Breuning, 1982).

This seems to suggest that the real training needs of direct service workers should focus on the specific medication needs of the people with whom they are working. Further, medication education should be placed within a

framework which emphasizes the need to have a long-term global vision of the best possible life for the specific individual. When this vision guides the provision of services there is a shift in focus away from the person as the source of a "problem" to the social context within which he or she has to live life.

Based on a perspective which sees individual behavior as just one element in a social context, Agran and Martin (1985) suggest that social validity (i.e., how a person is perceived and accepted in the community) is the ultimate test of any intervention. Implementation of this criteria emphasizes the crucial role played by the people who have regular daily contact with people with disabilities in the community settings where they need to function. When the issue is the need for or the effectiveness of medication the prescribing physician is dependent on the judgement of support personnel (i.e., direct service workers), friends, and coworkers to indicate whether a particular behavior is a serious hindrance to integration or merely some personal "quirk" which is social acceptable. As an example they point to instances where the hard data has clearly demonstrated a positive treatment effect, but the non-handicapped workers in the setting saw no change. They further suggest the use of nonhandicapped person inventories and discrepancy analyses as a primary source of information for aiding the clinician in making medication decisions. It seems that the development of these skills would make more

effective use of staff training time than memorizing the information in Table 1.

Finally, the role of the direct service worker, the roommate, the friend, or the family member as a spokesperson for an individual with limited communication ability cannot be over emphasized. When a psychotropic medication is prescribed for a person who does not have a developmental disability a primary source of data for the adjustment of dosage or change of medication comes from the patient. When a person is unable to speak for themselves it is imperative that someone who really knows that individual reports how a drug seems to change the person. While no data can ever be found to support this position, I am sure that the lack of a sensitive spokesperson is a major contributing factor in the toxic over-medication of people in institutions and the community.

Use of Community Physicians

In the final analysis the management of an individual's medication is matter which involves the person and his or her physician. It is true that some community doctors are not familiar with some of the concerns surrounding the medical care of people who have a history of life in an institution where they may have been exposed to Hepatitis B or been administered massive doses of unneeded drugs. Merker and Wernsing (1984) point out the important role of the community physician in the meeting the needs of these

people and they outline the major "specialized" medical issue which may arise. They indicate that the family practice with which they are associated has been able to meet these needs including management and reduction or elimination of psychotropic medications. Similarly in their research on the coordinated use of programming and medication in managing behavior, Schalock and his colleagues (1985) report that two community psychiatrist and 10 general practitioners were effectively overseeing the drug regime of the 41 subjects of their study. It is clear that a physician in general practice certainly can provide for the day-to-day care of a person who is receiving psychoactive medication. Nonetheless, the specialized knowledge relevant to these drugs probably requires that people taking them also be periodically reviewed by a community specialists whose practice regularly involves the monitoring of psychoactive drug regimes.

It seems that another role for the community service provider is to help make the match between community physicians and the people with a disability whom he or she serves. In addition to providing necessary personal information, this may entail providing some information from the medical literature which the physician is unlikely to have read (cf. Appendix). This could be done either individually or through the local medical society. It may include the Merker and Wernsing (1984) article, a form to assist in the monitoring of medication (Kalachnik, Miller,

Jamison, & Harder, 1983), the desciption of a procedure to eliminat medication and/or determine the minimum effective dose (Fielding, Murphy, Reagan, & Peterson, 1980), or a protocol for diagnosing tardive dyskinesia (Sprague et al., 1984).

Summary

If we look beyond researchers' penchant to point out the inadequacy of all previous studies, decry the paucity of studies in a particular area, and define problems which cry out for further research there are a number clear messages in the literature on psychotropic drugs.

1) Most people with severe disabilities do not need to be on behavior altering drugs. People with severe disabilities have been and continue to be the victims of over use of medication. They often are given unnecessary medication and even when the medication does appear to be called for they have been subject to over medication.
2) This standard practice does not aid integration. There is every indication the side effects of medication interfere with the ability of people to develop skills, work up to their potential, and relate well with those around them.
3) Widespread use of psychotropics is probably indicative of a program which is focused on controlling groups not on aiding the integration of individuals into the community. For the most part medication is used as a substitute for

an individualized approach to services. It is used to control people in group settings where staff are hard pressed to provide constructive functional activities for all the residents.

4) As in all aspects of human services the use of medication must be totally individualized. There is a small percentage of people with severe disabilities (just as there is a small percentage of the general population) who can benefit from a closely monitored regime of psychotropic medication. The monitoring physician must receive constant feedback about the effects of the drug from the person on the medication and from those who are closely involved with that person.

5) Management of psychotropic medication is a generic service which people with severe disabilities can obtain--just like everyone else--in the community. The use of medication does not mean that a person must receive medical care from an institution or "specialized" clinic. There are clear guidelines and several practical tools in the literature which enable physicians in general practice, working in concert with family members, direct service workers, and the individual with a disability, to manage the use of psychotropic medication.

Lovett (1985) has a reasonable even-handed discussion of the issues of medication specifically as they apply to community-based services for people with severe

disabilities. What is particularly noteworthy in his discussion is the emphasis on the role of the person with a disability in managing his or her own life including the use of medication. As he explains, and illustrates with case studies, even the use of psycho-active drugs with their connotation as a tool for "managing" people, can become a vehicle for personal growth and fostering an individual's self-image. In conclusion it seems worthwhile to quote his summary guidelines on the use of medication.

> A referral to chemotherapy should be sufficiently specific so that a person unfamiliar with the behaviors involved could recognize them from the description provided. The frequency of the behavior should be noted as well as any pertinent circumstances in which it occurs.
>
> Any medication should be administered with well-defined target behaviors listed and regularly reviewed. there should be a reasonable definition of what would constitute "success" for the medication as well as when such results could be expected. if medication that should be effective within 72 hours has produced no change after a week, it should be discontinued. If it has been effective, how long should the person be maintained on this before being given a "drug holiday"?
>
> The Physician's Desk Reference and a medical dictionary are helpful in getting accurate information about the possible side effects a given drug might induce.
>
> Data and information should be done in the same way the baseline information was so that changes that correlate with the medication or various dosages of the medication can be seen more clearly.
>
> After the target behaviors have been eliminated, then the drug should be removed to see if the behavior still exists. Drug holidays should be regularly scheduled to make certain that the original behavior the drug was intended for is controlled by the medication and by the medication only.
>
> The use of medication, just like any other approach, must always be the best form of assistance we can offer rather than simply being the easiest. (pp. 131-132)

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APPENDIX:

SOME USEFUL RESOURCES FOR COMMUNITY PHYSICIANS

An overview of the role of the community physician and special concerns as they relate to patients with developmental disabilities:

Merker, E. L., & Wernsing, D. H. (1984). Medical care of the deinstitutionalized mentally retarded. American Family Physician, 29 (2), 228-233.

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In addition, many of the references in this report, especially as they relate to issue such as withdrawal of medication, toxicity, and minimum effective dosage, may also be useful.